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**BEYOND BANDAIDS:** Delivering Healthcare Fit for Kids • • • Final Report | May 2024



Children's Healthcare Canada

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## Introduction



### The Problem

Canada is experiencing a crisis in child and youth health. Measurable decline in the health and wellbeing of the children in this country has implications at the individual, family, society and systems levels. Canada once ranked in the top 10 amongst OECD (Organization for Economic Cooperation and Development) countries with respect to children's health outcomes, however, the 2020 UNICEF Report Card 16 reveals Canada's standing has dramatically fallen from 10th in 2010 to 30th of 38 countries with respect to children's physical health and 31st of 38 countries regarding children's mental health (1).

There are many social and economic factors that impact a child's physical health and mental health, but to reach their full potential, children and youth require timely access to high-quality primary, specialty, and tertiary/quaternary healthcare. And yet, today in Canada, many children are waiting longer for essential health services across the continuum of care than adults (2, 3).

The continuum of care represents a comprehensive array of health services spanning all levels of intensity of care. As it relates to child and youth healthcare services and in the context of this report, the continuum of care refers to primary care, specialty care (including but not limited to homecare, residential and respite care, palliative care, child development services, rehabilitation services, and mental health services), and tertiary/quaternary care (hospitalbased care delivered in community, regional, and academic health centres, including children's hospitals). While the proportion of children living in Canada has not increased significantly over the last 20 years, the population of children is growing. By 2040, it is anticipated that Canada will be home to nearly 9.2 million children and youth (1.2 million more than in 2021) (4).

Healthcare delivery organizations serving children and youth are experiencing unprecedented demands for their services. Many children's hospitals across the country are now routinely operating at or above one hundred percent capacity (5, 6), while pediatric programs in community hospitals are being squeezed to meet the demands of adult (increasingly, elderly) populations. The shortage of primary care providers in office-based practices means reduced capacity and resources to meet the demands of a growing population of medically complex children and youth (7). From coast to coast to coast, children are languishing on wait lists for essential and time-sensitive healthcare interventions, from child development assessments to community-based mental health services and acute surgical interventions (8, 9).

There is no simple solution to tackle the long healthcare delays children, youth and families are facing. The current reality has been decades in the making and can be attributed to several complex factors, including sociodemographic changes within the broader population, advances in science and medicine, changes within the healthcare workforce, and the increasing health and

social complexity amongst children and youth presenting for care (10). Over time, healthcare systems have done their best to evolve organically to meet changing needs. In best case scenarios, healthcare delivery organizations have developed relationships and infrastructure to coordinate care and share information across settings, particularly for children living with medical complexity, or chronic illness. More often than not however, care remains fragmented making navigation a complicated or complex challenge that often lands on the shoulders of exhausted parents or caregivers.

Further exacerbating the challenges above are the funding models for children's healthcare services across the continuum of care, and the remuneration of pediatric subspecialties. Funding models (which vary across provincial and territorial jurisdictions) remain stubbornly fragmented, leading to persistent silos across services and sectors. Access to pediatric subspecialty care is threatened, in part, by relatively low salaries, which creates a limited supply of new entrants into the workforce, particularly in the non-procedurally based pediatric subspecialties. The financial realities of medical school debt coupled with the high cost of living in many of the cities in which these providers practice, create very measurable financial disincentives to choosing a career in pediatrics (11).

Some institutions (predominantly community/regional and children's hospitals) benefit from philanthropy to build capacity for service delivery and support the purchase of specialized equipment. In Canada, children's hospital foundations are now the single largest non-government funder of children's healthcare (12). Not every healthcare delivery organization serving children benefits from a foundation, leaving many persistent funding gaps, particularly outside of tertiary care settings.

As a wealthy nation, Canada disproportionately and systemically underinvests in child and youth health and wellbeing compared to other countries. Canada currently invests 1.68% of its Gross Domestic Product (GDP) on policies and investments towards children and youth. In comparison, countries like France, the United Kingdom, and Sweden invest up to 3.68% of their respective GDPs and rank higher than Canada on the 2020 UNICEF report card (1).

#### Change is necessary.

Canada is ignoring the needs of children and youth to its own detriment. The costs of inaction and underinvestment are predictable, measurable and staggering. A 2023 research series commissioned by Children's Healthcare Canada reveals significant financial and human costs linked to delays in children's health services (13, 14). Whether it's the yearly \$4 billion expenditure to provide care to children and adolescents with anxiety and depression, the projected trilliondollar expense over a lifetime for neglecting early indications of mental health issues, or the substantial lifetime costs of failing to provide timely support for children with autism, currently estimated at \$8.2 to \$11.1 billion, the economic impact is profound.

Simply put, the status quo is not an option. Our historically siloed, patchwork approach to tackling the complex health and social needs of children, youth and families is failing kids, their healthcare providers, and quite frankly, the future of our country.

# A Vision for the Future

People living in Canada imagine a healthier future for their

children, and they expect governments, child health advocates,

healthcare professionals, and the organizations they work for to play a role in realizing this vision. In 2023, Abacus Data found that 94% of Canadians agree that it's time to improve healthcare systems to better meet the needs of children and youth. It's time for collective action to meet that level of expectation (15).

In 2023, a pan-Canadian consultation led by Children's Healthcare Canada (CHC) and the Potential Group engaged a diverse cohort of children's healthcare leaders, family partners, youth, child health researchers, data analysts, and children's advocates. The goals of this consultation were: to develop concrete recommendations for improved, integrated systems of child and youth health services and care across Canada; to improve health outcomes and create sustainability in the system; and, to guide goals, policy, advocacy efforts and investments in healthcare across Canada.

A simple vision statement quickly emerged:

### Accessible, equitable, connected healthcare services designed for the needs of children, youth and families in Canada.

This desired future would include:

- A safe, inclusive, and healthy environment; stable housing; food security; education; friendship, inclusion, and belonging, with family who are equipped and supported to create physically and emotionally resilient atmosphere, and where leaders are acting to address climate change;
- Universal health promotion, prevention, and screening in schools and community settings that foster healthy practices and belonging for parents and kids, and enable early intervention for physical and mental health needs;
- Team-based primary care close to home and fully integrated with specialized health, community, and social services;
- Rapid access to child-friendly healthcare in every setting, including community hospitals, and, when needed, to sub-specialized pediatric care without delays;
- Family and care provider partnerships that enable access to knowledge to support informed decision-making about options and care pathways; and
- Seamless care and services across the lifespan, with supported transitions into adulthood.

A series of recommendations targeting governments (federal, provincial and territorial), child health advocates, and child healthcare delivery organizations were articulated to achieve this vision. These recommendations lay the foundation to improve children's and youth's healthcare experiences, and importantly, their health outcomes.

Improving the health and wellbeing of children, youth and families will require efforts, investments and collaborations that extend beyond healthcare systems into all aspects of daily life and the social determinants of health. Without interconnected, well-resourced, sustainable systems to provide physical and mental health care services across the continuum of primary care, community settings, acute care, and rehabilitation, children, youth and their families (and indeed, our nation) will not achieve their full potential.

#### About this Report

This report delivers recommendations for governments (federal and provincial/territorial), children's health advocates, and healthcare delivery organizations to support transformative change to improve children's health systems. The report collates findings from two initiatives undertaken by Children's Healthcare Canada (CHC) between 2022 and 2024:

- 1. An economic impact analysis commissioned by CHC, conducted by the Conference Board of Canada. This study quantified the financial and human costs associated with long waits that children and youth are experiencing with respect to essential healthcare services.
- 2. Findings from a broad virtual consultation conducted by the Potential Group in partnership with CHC, resulting in over 600 touchpoints with health system leaders, family partners, data analysts, child health researchers, and others. The consultation aimed to develop concrete recommendations for improved, integrated systems of child and youth health services and care across Canada; to improve health outcomes and create sustainability in the system; and, to guide goals, policy, advocacy efforts and investments in healthcare across Canada.



# Building Blocks for Successful Health Systems Transformation for Children and Youth



Throughout this report, the reader will note perspectives that emerged from virtual consultations with Children's Healthcare Canada members, family partners, and researchers. These thoughts and perspectives reflect lived experiences that can help to guide the path forward towards more accessible and equitable health systems for children and youth.

Children's Healthcare Canada's consultations revealed three urgent and foundational building blocks to meaningfully, measurably and sustainably begin the process to transform health systems for children, youth and families.

#### Building Block # 1

### Dedicated and protected funding envelopes for children's health systems

across the continuum of care, including child health research.

Canada's healthcare systems serving children, youth, and their families are currently undersized. There is insufficient funding allocated to children's health systems (including child health research), and a shrinking highly specialized workforce to meet the needs of a growing, increasingly complex and diverse population. For many years, children in Canada were thriving as a result of world-class research, medical advances, and strong public health policies. As a result, they required fewer and less intensive healthcare services. Governments predictably began reallocating healthcare funding traditionally earmarked for youth and children to adult populations. The proportion of health dollars spent on children and youth began to shrink — despite a growing population with increasing rates of mental and behavioural health diagnoses, obesity, and other chronic diseases (16).

Most recently, the COVID-19 pandemic coupled with a historic viral season created unprecedented pressures, making it clear how fragile children's healthcare systems are and how vulnerable many children living in Canada now are. In many jurisdictions, children wait longer for essential services than many adults. Sadly, these delays in access have been normalized, despite their associated significant financial and human costs (16).

Recent research conducted by the Conference Board of Canada and commissioned by Children's Healthcare Canada reveals that the costs of inaction are measurable and significant. One report examining the costs of long delays in access to children's mental health services (specifically those to treat anxiety and depression) conservatively estimates Canada spends \$4 billion annually as the result of incremental costs to publicly funded health systems, the education sector, justice systems, and forgone employment income of parents and caregivers (13).

The report confirms 1.6 million children and youth living in Canada have a diagnosis of anxiety or depression, a number that almost certainly underestimates prevalence given challenges associated with accessing mental health services such as timely assessments, diagnoses and treatments. Further, the report indicates that children and youth who are Black, Indigenous, people of colour, and those navigating their sexual and gender identities face disproportionately higher rates of anxiety and depression, placing them at elevated risk. "We are running our entire healthcare system at or above 100% capacity, which leaves no room for crisis, research, or learning. To avoid constantly running so close to the wire, we need collective advocacy and action. We need to purposely build resilience into these systems."

Delegate, Children's Healthcare Canada 2023 Conference

Without timely investments, the lifetime costs of children experiencing anxiety and/or depression at the age of 10 years are projected to approach \$1 trillion. The report underscores the importance of early investments to bend this cost curve: investments today in child and youth mental health could save Canada \$28 billion annually (13).

Further research conducted by the Conference Board of Canada examined the costs associated with delays related to surgical interventions, and specifically scoliosis (a common childhood condition) (14). In Canada, many children wait beyond the medically recommended window for surgical procedures. The problem has persisted for years but was made worse by the COVID-19 pandemic. According to data from 2018, only 35% of non-emergent elective surgeries in Canada's children's hospitals were completed within the recommended time frame (17).

"Children are not small adults. We need a system that is purpose-built for kids, with funding that isn't constantly eroded by adult needs, and with measurable outcomes that allow us to understand what's happening with kids' health and plan accordingly."

Participant, Consultation 1

The report concludes that delayed pediatric scoliosis surgery, based on the number of children currently waiting beyond the medically-recommended window, cost the healthcare system \$44.6 million annually and leads to caregiver productivity loss of \$1.4 million.

Investing in health systems across the continuum of care is one of the most effective ways to improve children's access to essential healthcare services. To help children survive and thrive, health systems need sufficient funding to be sustainable, resilient, and inclusive (18). To meet the increasingly complex healthcare needs of a diverse population of children and youth in Canada, a new approach to planning and funding children's healthcare services is needed. Recognizing the transformative change that is required, an evidence-informed, integrated, cross-sectoral approach is necessary to yield desired results. In February 2023, the federal government announced an investment of \$2 billion to immediately top-up the 2022-23 Canada Health Transfer payments with the intent of addressing "a pediatric crisis." To date only two jurisdictions (Ontario, Nova Scotia) have committed new funds to improve access to children's health services. The unrestricted nature of these funds means that it is possible, if not likely, these monies will be redirected towards other uses (19).

Even with an injection of new resources, children's healthcare leaders from across the country agree that more is needed. Long-term sustainable and predictable funding would allow healthcare systems to implement and evaluate new models of care, address lengthy backlogs, recruit and retain sufficient numbers of highly specialized healthcare workers, and build interoperable data platforms. Ultimately this funding would improve access to healthcare information, inform decision-making, and facilitate child health research.

Successful transformation of health systems serving children requires that the federal government declare children's health and healthcare a national priority. Further, to improve access to and experiences of children's physical and mental healthcare services, the federal government needs to establish a dedicated fund to be administered in collaboration with its provincial and territorial counterparts.

This fund could be modeled on bilateral agreements the federal government signed in 2024 with the provinces of British Columbia and Saskatchewan focused on Aging with Dignity (21). The BC agreement saw the transfer of \$733 million over five years to improve access to home, community, and long-term care for seniors living in the province. In Saskatchewan, the commitment towards the same totaled \$169.5 million over five years (22). These funds' impact and progress towards locally-developed targets will be measured and publicly reported. This model provides inspiration for similar funding envelopes targeting the unique, and highly specialized needs of children and youth across the continuum of care.

#### Building Block # 2

### Publicly accessible child health data, captured under national health data

strategies.

Canada currently lacks an integrated, intentional approach to the collection of health data for children and youth. Existing data on access to and effectiveness of the health system is limited by the fact that most children's healthcare takes place in settings that also serve adults, with budgets and resources that blend pediatric and adult care.

"We have inadequate information on a spectrum of health outcomes and factors ranging from child and youth mental health to race, ethnicity, child maltreatment and parent health. As a country, we need to expand and enrich our ability to coordinate data collection, management and analysis. Then, we need to embrace evidence-informed policy and practice to bridge the gap between research and the design and delivery of policy and practice that can improve lives." (23)

Throughout virtual consultations hosted by the Potential Group in collaboration with Children's Healthcare Canada, participants acknowledged that Canada does not have the data necessary to facilitate specific projections for future funding and workforce needs.

A report issued by Senator Rosemary Moodie in February 2024 identifies the lack of consistent, accessible and comparable data as a challenge facing systems and sectors that support children and youth, and which could be impeding children's health and wellbeing outcomes (24). "The collection and analysis of data to ensure accountability of follow through of government is necessary", says the report. The report indicates that specific and measurable outcomes are currently lacking for children and youth related to mental and physical health and the healthcare systems that serve them.

In 2022, the federal, provincial and territorial governments announced the development of a pan-Canadian health data strategy "to support the effective creation, exchange and use of critical health data for the benefit of Canadians and the health and public health systems they rely on." (25) Governments acknowledge the important role reliable, relevant and timely data play improving health outcomes for all people in Canada - which includes children and youth.

Data play a critical role in informing our understanding of children's current health status, demographics, needs, system capacity, and in establishing goals and targets related to health service delivery, and health outcomes, and monitoring progress towards them.

To enhance program delivery, strengthen policies, and target investments, children need to be an intentional focus of an accessible national health data strategy. Canada needs comprehensive, accessible, national child health and healthcare enable shared benchmarks. data that accountability, and integrated, measurable outcomes. Without this foundational data, nothing will change.

"We need to create a national child health data system that includes measures related to equity with a minimal data set that is regularly and consistently collected, and accessible to those charged with policy development and health services planning."

Participant, Consultation 2

#### Building Block # 3

The highly specialized health workforce that cares for children and youth

must be an intentional focus of national health workforce planning

initiatives.

When children require preventive care or experience illness, injury, or a limitation in their functioning, a wide variety of highly specialized healthcare and other professionals provide expert care to maintain, improve, and promote their health and wellbeing (26). This workforce includes, but is not limited to: pediatricians (ranging from community-based to highly specialized sub-specialists), pediatric and sub-speciality (e.g., Neonatal and Pediatric Intensive Care Units, Emergency) nurses and nurse practitioners, child development and rehabilitation specialists, occupational therapists, physiotherapists, speech-language pathologists, primary healthcare

professionals (e.g., family medicine physicians, nurse practitioners, and community-based pediatricians), social workers, community and public health professionals, and parents or caregivers who have been trained (or have had to learn) to fill professional roles (27).

Workforce challenges represent a significant and limiting constraint to children's healthcare service delivery and improvement and are a critical and necessary condition for successful systems transformation (28).

#### "Healthcare systems will flourish when they focus on people – with healthcare providers, children, youth, and their families at the centre - –and provide those people with adequate supports"

Dr. Katharine Smart, CHC Annual 2023 Conference

There have been longstanding concerns about the healthcare workforce pipeline to ensure sustainability of the healthcare services for children and youth. The COVID-19 pandemic has exacerbated existing challenges and created new ones within the broader health workforce. This has resulted in an imbalance between the supply of healthcare providers trained to meet the current needs of children with the demands of children themselves. This imbalance will only grow as the population of children grows and their future healthcare needs rise. The shortage of workers, many who have become ill, burned out, resigned or retired early, or who shifted (either voluntarily or by necessity) to care for adults, is contributing to long waits for many essential and time sensitive healthcare interventions for children and youth. Financial disincentives for pediatric subspecialists (regarding relative pay-inequity compared to adult care subspecialists) also creates barriers to access for children's health services.

"Pediatric care is very much a "team sport" that requires exceptional coordination between well-trained physicians, and skilled and experienced nurses, therapists, family partners, and many, many others."

Participant, Consultation 3

A cornerstone of healthcare systems fit for kids includes a workforce purpose-trained to deliver care for this population. Children and youth require accessible and efficient health systems that enable them to receive the appropriate type and amount of primary, community, and specialty care whenever they need it. For this to happen, Canada needs a robust, highly specialized, equitably remunerated, multi-disciplinary workforce.

# Recommendations to Advance an Action-Oriented Agenda for Transformation

In addition to the three building blocks identified above, and to realize a vision of healthcare systems fit for kids, the federal government, provincial and territorial governments, child health advocates, and children's healthcare delivery organizations (including family partners) must be meaningfully engaged. They each have interdependent actions to take.

### **Roles and Responsibilities**

#### **Federal Government**

The federal government has an important leadership role to play in catalyzing and supporting children's health systems transformation.

#### Recommendation #1

### Create and implement a pan-Canadian children's strategy that includes targets and timelines to improve children's health outcomes.

Children's Healthcare Canada recommends the federal government works with provinces and territories, children's advocates, child health researchers, family partners, and healthcare system leaders to develop a pan-Canadian children's strategy. This strategy should articulate clear outcomes-based targets for children's health and healthcare, a timeline to achieve these targets, earmarked funds to realize this vision, and a public reporting mechanism on progress.

This strategy must be evidence-informed and underpinned by a strong, integrated, and sustained child health data and research strategy to achieve its short-, medium-, and long-term goals. The Inspiring Healthy Futures framework, co-created by over 1,500 cross-sector civil-society organizations, youth, family partners, researchers and others, provides an important foundation for this strategy (29).

#### Recommendation # 2 Establish an office for a Chief Children's Health Officer.

Children's Healthcare Canada and 17 collaborating national healthcare organizations propose establishing the Chief Children's Health Officer within the Ministry of Health (30). The role would be responsible for implementing a national children's strategy, enabling a cross-departmental approach to child health and wellness, and facilitating necessary collaboration on shared

#### Inspiring Healthy Futures

A Vision for Canada's Children, Youth and Families

In 2020, CHC, UNICEF Canada, the Pediatric Chairs of Canada and the Canadian Institutes of Health Research-Institute for Human Development, Child (CIHR-IHDCYH), and Youth Health convened over 1,500 strategic partners to co-create a vision and roadmap to measurably improve children's health and wellbeing. The partners included youth, parents, researchers, educators, advocates, policymakers, healthcare and social service providers, community and business leaders, and others. Inspiring Healthy Futures is a collective action framework, centered around mobilizing youth with an aim to shape and inform research collaborations, child-centred policy, adaptable and accessible health systems and school and community hubs. For more information, visit www.inspiringhealthyfutures.ca

priorities with provincial, territorial, and Indigenous governments. The Chief Children's Health Officer would collaborate civil with society organizations and healthcare professionals across the continuum of children's healthcare. The office would be instrumental in highlighting and advancing pan-Canadian solutions that address systemic challenges. Just as Canada has created important roles such as the Chief Dental Officer, Chief Public Health Officer, and Chief Nursing Officer, this type of role and office should also exist for children's health given that children are the future of Canada. Currently Canada lacks this robust governance structure specifically designed to prioritize children's health and wellbeing.

As referenced previously, Canada was once a top-ten performer within UNICEF's international rankings and has fallen significantly with respect to measures of children's physical and mental health. Countries that routinely rank highly on the UNICEF indices have three things in common: they have

declared children's health a national priority, they have made deliberate and sustained investments in children's health and wellbeing, and they have identified a leader accountable for measurably improving health outcomes. Canada has yet to make similar commitments.

#### Recommendation # 3 Create a dedicated and earmarked funding envelope to ensure a robust maternal, child, and youth health research agenda.

Children's Healthcare Canada consultations revealed deep alignment with a vision for children, youth and families to experience the best possible health and well-being, informed by highquality research that is interdisciplinary, built on strong partnerships and integrates their needs and voices (31). To realize this vision, CHC recommends the federal government make an explicit commitment to fund research in maternal, child and youth health. The link between a nation's economic health and the health of its citizens is well established. Health research plays an important role in our collective ability to attain good health and minimizes the impact or burden of disease, including public health threats such as COVID-19 (32).

While investments in children's healthcare and health systems are needed, doing so without a corresponding investment in health research will fail to achieve sustained improvements to health. In short, health research must be part of the solution.

Canada has historically played an international leadership role with respect to children's health research, contributing world-class research findings to better understand determinants of good health and a myriad of health conditions, including children's health and disease outcomes. We are fortunate to have world-leading talent and great potential in research and development, but this country runs the risk of squandering this excellence without further investment in health research. This investment in research should be dedicated to children, youth, and their families with focus on better beginnings, vibrant childhoods, and empowered youth.

### **Provincial and Territorial Governments**

Provincial and territorial governments play an important role as an administrator and payor of healthcare service delivery, in accordance with principles defined in the Canada Health Act. As such, there are several recommendations for provinces and territories to ensure healthcare systems are serving the needs of children and youth, their families and caregivers, and the children's healthcare workforce.

#### Recommendation #1

## Leverage Canada Health Transfer funding to address the ongoing crisis and build capacity in systems across the continuum of care.

To date, only two jurisdictions (Ontario and Nova Scotia) have made public commitments to bolster funding for children's health systems following the 2023 federal announcement of \$2 billion to support the "pediatric crisis." Provinces and territories are urged to leverage these funds for their intended purpose, creating new and sustained capacity in healthcare systems (including, hospitals, children's treatment centres, home care, palliative care agencies, and respite care providers) serving children and youth.

#### Recommendation # 2

Collaborate with the federal government to support the development and implementation of a Pan-Canadian Children's Strategy, complete with targets and timelines to achieve measurable improvements in children's health and wellbeing.

A pan-Canadian children's strategy will require the engagement and support of the provinces and territories to be impactful. Recognizing that provinces and territories have unique strengths and face their own challenges related to children's health, healthcare, and health outcomes, a national children's strategy would define clear evidence-informed, outcome-based targets and timelines and provide jurisdictions the flexibility to advance local priorities. Provinces and territories should be accountable for reporting progress towards locally-defined goals.

#### Recommendation # 3 Establish virtual care guidelines, practices and compensation for faster access to specialized care.

The pandemic has proven that virtual care is a viable and sometimes is a preferred option for delivering and/or accessing healthcare services. Provincial frameworks have been developed and implemented ad hoc and inconsistently. A robust national framework and a unified approach is necessary to enable high-quality virtual care that provides timely service to children and youth. This framework would facilitate sub-specialty clinical consultations with healthcare professionals in communities that lack such providers and define appropriate compensation for healthcare providers to improve quality and equity in access, experiences, and outcomes of care for children and families across Canada.

#### Recommendation # 4

# Facilitate timely access to universal screening, early identification, and intervention without delay to address healthcare needs, particularly for mental health and developmental needs.

Twenty percent (20%) of Canadian children aged 4–17 years struggle with mental disorders at any given time, yet mental health providers reach only 25-33% of these children with preventable and or treatable anxiety, ADHD, substance misuse, behavioural disorders, and depression (33-35). Without early diagnosis and intervention, these disorders then often persist into adulthood, causing symptoms, impairment and great distress which prevent young people from reaching their full potential.

Coordinated leadership is required at the national and provincial/territorial levels, that focuses on comprehensive long-term plans to provide effective and increased access to assessment, diagnosis and treatment options in schools, primary care settings and community-based services for all children who require them. Applying a public health approach where we promote healthy development for all children can lead to prevention of disorders in childhood (36).

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#### Recommendation # 5 Identify a designated primary care provider for every child before birth.

Recent estimates suggest 20% of Canadians of all ages do not have a primary care provider, and 30% of those who do are unable to schedule an appointment in a timely fashion (7).

The population of children and youth in Canada continues to grow, and the complexity of care they require is also increasing. Ensuring every child in Canada is designated a primary healthcare provider before birth means routine screening, preventative care and care of chronic conditions will be managed as soon as they are born, resulting in optimal health outcomes for every child, youth, and family.



The Public Policy Forum released a set of recommendations (must – dos) for urgent primary care reform in Canada that would lead to increased access to equitable primary (37). These must-dos include, but are not limited to, changes to compensation and incentives, data collection and measurement, process automation, adoption of team-based primary care, and national licensure of health professionals (37).

Governments need to work with the schools of nursing and medicine, the professional colleges and healthcare professionals, and families to design and implement policies and programs that support the growing need for accessible primary care in Canada.

"We know that we can't have comprehensive sub-specialized pediatric care in every rural or remote setting, but we need to get creative about how we use virtual care, rapid transport and partnerships between specialists and community providers to deliver better care when we're far away from urban centres."

Participant, Consultation 5

#### Recommendation # 6 Create cross-ministerial commitments to recognize families as an essential part of the children's healthcare workforce, supported by flexible financial resources and practical support.

One in four people in Canada is a caregiver who provides an average of three hours of care for every hour of care provided in the healthcare system (38). For families of children with medical complexity or chronic conditions, this investment of time increases significantly.

Families and caregivers require greater financial support, including simple access to tax credits, income replacement, and expanded home and community healthcare services. For employed parents or caregivers, provinces and territories should strengthen and explore policies, benefits, and legislation that would support and enhance flexibility (e.g., leave policies) in working environments to help improve the healthcare experiences and health outcomes of children and families.

"We need joint accountability that we are all in this together to delivery collectively on the wellbeing of children."

Delegate, Children's Healthcare Canada 2023 Conference

### **Child Health Advocates**

In this context, child health advocates include those with a vested interest in improving children's health outcomes, and the health systems that serve children, youth and their families. Advocates may include civil society organizations with a focus on children's health and healthcare, youth and family partners, members of the child health workforce, health researchers, and philanthropists. Child health advocates play an important role serving as subject matter experts, and as convenors of those with shared priorities with the means to influence change.

#### Recommendation #1

Elevate child health and healthcare priorities to ensure that the Canadian public, media partners, policymakers, and others understand the critical challenges facing children, youth, and their families in Canada, and the tangible solutions available to improve outcomes.

Child health advocates (organizations, networks, individuals, and patient partners) should align efforts to advance health system integration, coordination, and transformation to be most effective. The more consistent the narrative and proposed priorities for transformation, the more likely real change will occur.

The Inspiring Healthy Futures initiative defined "accessible and adaptable health systems" as a necessary condition for children, youth and families to thrive. The strategic goals defined within the framework, and those co-created by children's champions within this body of work, provide a timely focus to underpin collective advocacy (29).

#### Recommendation # 2 Engage the philanthropic community to improve children's healthcare services across the continuum of care.

In Canada, philanthropy and corporate giving play an essential role in supporting the delivery of health care services for children and youth, enabling innovative research and discovery, and creating healing environments for kids and their families. Each of the sixteen children's hospitals in Canada is supported by a foundation and collectively these foundations raise tens of millions of dollars annually from partners, programs and donors. Large academic community and regional hospitals also benefit from fundraising support from their respective foundations, though the allocation of funds directed to pediatrics varies considerably.

To maximize impact and build capacity across health systems serving children and youth, philanthropic support is required across the continuum of care.



### **Children's Healthcare Delivery Organizations**

Children's healthcare is delivered across a variety of settings. From everywhere in between small respite care homes to large tertiary and quaternary care hospitals, organizations and professionals that are providing healthcare services to children and youth are resilient, resourceful, and committed to providing the best care possible. Children's healthcare delivery organizations are dedicated to enhancing service delivery and improving children's healthcare access and experiences as well as health outcomes. This happens through continued collaboration, improved integration, and collective planning and action to identify or co-develop solutions to common challenges.

The recommendations that follow were crafted through Children's Healthcare Canada's virtual consultations with the children's health workforce (including family partners). These recommendations are not new to those delivering healthcare services to children, youth and families. The recommendations are currently in various stages of implementation across the country, and at different stages of maturity. The aim is for the sector to work collectively towards these pillars of high performing health systems, learning from efforts underway to improve and accelerate capacity to deliver safe, more inclusive and adaptable care for all children in Canada.

#### **Recommendation 1:**

Design healthcare systems holistically, spanning physical, social, and mental health needs.

#### Recommendation 2:

Build purposeful partnerships that enable integrated care pathways for kids and families with medical complexity, chronic conditions, or neurodiversity.

#### Recommendation 3:

Expand localized capacity and innovative models for children's healthcare in rural, remote, and Northern communities.

#### Recommendation 4:

Work toward an "ecosystem of care" for shared resources, centralized referrals, child health research, knowledge mobilization, and implementation for timely access to quality healthcare.

#### Recommendation 5:

Expand guidelines and education that drive child-centred, culturally inclusive healthcare practices, across the continuum of care, in all healthcare settings.

#### Recommendation 6:

Integrate electronic medical records and/or health information systems around specific needs of the children's health workforce, including parents and caregivers.

#### Recommendation 7:

Develop technology-enabled navigation for more timely, integrated access to children's healthcare and social services.

#### Recommendation 8:

Design transitions to adult care that match the needs and capacity for each child and youth.

# Conclusion



### Every day matters in the life of a child.

Measurably improving the health and wellbeing of children, youth and their families will require fresh thinking, brave ideas, and bold new collaborations. In 2021, Inspiring Healthy Futures concluded that life for children and youth in Canada will not improve until or unless we take action to advance five interlinked priorities: implementing child-centred policies and structures, leveraging schools and communities as hubs of health and wellbeing, undertaking impactful research and knowledge creation, mobilizing communities around children, youth and families and creating accessible and adaptable health systems (29).

This report aims to advance an action plan to address the latter priority, acknowledging the crisis that is unfolding in Canada's healthcare systems and the window of opportunity we have to build capacity to meet the needs of children in this country. Without interconnected, well-resourced, sustainable systems to provide physical and mental health care services across the continuum of primary care, community settings, acute care and rehabilitation, children, youth, their families and healthcare providers will not flourish. Indeed, a generation of children and youth are at risk of significant long-term health problems without immediate action (39).

Better is possible. Canada is a wealthy country with all the resources necessary to improve children's health outcomes. By mobilizing strategic partnerships from all levels of government, advocacy, and the health sector, coordinating the deployment of new resources with a focus on children's health, and creating leadership for change, we can move beyond bandaid solutions to create healthcare systems fit for kids.

"We want to create a world where children and their families are flourishing, and we want a healthcare system that allows the people within it to flourish as well."

Dr. Katharine Smart, 2022

### About Children's Healthcare Canada



Children's Healthcare Canada is a national association serving children's healthcare delivery organizations across the continuum

of care. Our membership includes all sixteen of Canada's children's hospitals, in addition to community and regional hospitals, child development centres (children's treatment centres), and respite, palliative and home care agencies serving children and youth. We exist to accelerate excellence and innovation in health systems serving children, youth and their families in Canada.

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